

Spider Web Walking: Hope for Children with FAS Through Understanding

Jan Lutke

A few months before I was asked to write this chapter, a remarkable thing happened. My daughter, who was 12 at the time, had been asked to speak to a group of teachers about what it was like to have FAS. She asked me if she could practice what she wanted to say, using me as her audience. She proceeded to draw for me and explain the wonderfully apt analogy that is the basis for this chapter. She uses this analogy to explain FAS, and she calls it "spider web walking." She drew a picture of a very lopsided spider web of big holes and broken strands. This web represented her brain. She explained to me that having FAS was "like having a broken spider web in my brain. Sometimes I get to stick just right and I can do it, and sometimes I fall through the holes and I can't." I was amazed at her perception and questioned her further. I asked her if the reason she "fell" was because she could not do the task at hand. She very carefully explained that I had misunderstood her. The reason she could not do the task was precisely because she fell. In other words, the fall came first. I sat mesmerized as she told me how she had to "walk" on the spider web and how difficult that was. She had just summed up accurately, in a few minutes, what had taken me years of concentrated thought and effort to learn! All this from a child who is still unable to do multiplication tables, cannot tell time, and does not know left from right. Miracles do happen, if we but take the time to hear them.

I remember very clearly the day, more than ten years ago, when I began the process of understanding what "spider web walking" meant for the affected individual. I happened to be flipping through a dictionary, looking up the word "accessory." In one of those minor detours from a task we all take, memorable only for the inconsequential nature of the event, my eyes were drawn to the word "abstract." I read the definition, which I remember as "a thought apart from any particular object or real thing, but somehow related to it - a lump of sugar is real; the idea of sweetness is abstract." I was intrigued by this definition. I sensed that I was on the edge of something important to my understanding of how children with FAS seemed to act, but I was not sure just what it was.

At the time, I had over 10 (now over 20) year's experience in dealing with the behavioral and emotional challenges related to issues of abuse and neglect in adopted and foster children; in fact, dealing with these issues had become a way of life for me. I gradually was incorporating into my normally good parenting skills an awareness that children with FAS were different - in how they approached just about everything - from other behaviorally and emotionally challenged foster children. I had parented children diagnosed with FAS for over five years. I had read everything I could about FAS, gone to workshops, liaised with medical professionals and other parents, and was in the beginning stages of setting up a support network. It was a "teachable moment" for me - I was open to hearing and seeing things differently.

Experience over the years has taught me the value of moving slowly. I decided to let this thought on the elusive nature of abstraction sit and percolate for awhile. Over the next few months, I spent a lot of time thinking about this idea. Children with FAS have great difficulty with abstraction and conceptual thinking, and I thought about the relationship of the nature of abstraction to the intervention strategies that I used. I knew that these strategies worked, but I came to understand that I really did not know why they worked, except in the most cursory way. They were "successful accidents."

It occurred to me that I should give equal consideration to the "concept" piece of the equation. What are concepts anyway? Where do they come from? Why do we have them? Concepts are ideas which are formed and understood in the mind - this seems obvious. What may be less obvious is that the mind is the only place a concept exists. Even more obscure is the process of conceptualization.

We often try to work in the middle of a problem, instead of figuring out where its beginning is, and I wanted to get to the beginning of the problem of understanding children with FAS. I was struck by the obvious but still elusive applicability of these definitions to what we see with FAS. What intrigued me was the idea that these definitions were important to understanding the specific problems children with FAS seem to have, especially social and behavioral problems.

The end result of this personal learning process that I just have described has been the development of an operational paradigm for understanding and intervening with FAS based on these fundamental components of "spider web walking." Understanding and using conceptual thinking, understanding cause and effect, generalizing information, understanding time, and utilizing short-term memory. To deal effectively with life itself, to be able to function, one must be able to use these processes on a very sophisticated level of accomplishment. We take these processes for granted. If people with FAS are unable - not unwilling - to do this on our terms, in our ways, is it possible that they could use external processes to replace those internal ones which they do not have?

Problems with Understanding and Using Conceptual Thinking

Abstractions and concepts work together to simplify and put order into what would otherwise be a world of overwhelming complexity. Concepts provide guidelines and parameters for our functioning, and usually are taught parent to child, generation to generation. Social values for human interaction are concept-based. Accurately understanding and using concepts permits an individual to understand what is required of him/her in a particular situation and to predict how he/she will need to act in future similar situations.

Using concepts allows one to predict the how, what, where, and when of an interaction. I understand that the concept of "one" can be 24 (one day) or 7 (one week) or 30 (one month) or 365 (one year), depending on which concept of "one" I am using at that moment. I understand the concept of the word "if" and when to apply that idea. I understand that a moving car is real, and that the concept of danger associated with that car is also real, even though I cannot see, hear, or feel that danger. There are many different variables which determine the level of danger in any given instance, including what I do. I am lucky. My brain *automatically* sorts through what it knows about a particular situation and, unless I am very unlucky, comes up with the right choice for action. For the person with FAS, this critical process of understanding and applying concepts and abstractions to particular situations is neither automatic nor consistent. "Spider web walking" becomes difficult and fraught with pitfalls.

Problems with Memory

People with FAS often have difficulty with storage, integration, or retrieval of information, and this difficulty has a negative impact on one's ability to adequately and accurately address a situation requiring a response. For people with FAS, information sometimes is stored in a random, haphazard fashion, with no predictable order. Even when information is stored in the right file cabinet under the right file code and in the right file, it tends to "get lost." It seems to disappear without warning, only to reappear, unpredictably, right where it should be. These unpredictable memory lapses and gains happen just often enough to convince those who do not understand FAS that they are deliberate "behaviors" under the control of the person with FAS. The reality is very different. No one is more frustrated by this situation than is the affected person, who must continually deal with the reactions of other people. Telling the truth, making sense of situations, and responding to requests become difficult. Even when information has been successfully stored and accessed the individual with FAS must be able to interpret what he or she needs to do with that information. "Lying" is a by-product of these difficulties. It occurs when interpretation of what was originally stored incorrectly runs headlong into a distorted perception of the environment and one's relationship to it.

Understanding Cause and Effect, Generalizing, and Problem Solving

For people with FAS, an understanding of the relationships between cause and effect can be missing altogether, available only sporadically (when you stick on the spider web), faulty, or just not an automatic process. Linking causes with effects, and remembering these links, allows one to generalize information from one situation to another. The ability to generalize information is a basic prerequisite for problem solving. It allows one to be flexible and to check out possibilities and shift them around - an important middle step in any problem solving process. Looking at all the pertinent factors which apply to a situation allows one to come up with the appropriate action for a situation. If you do not have the ability to think about different possibilities, your ability to make good choices based on possible outcomes will be altered.

People with FAS often do not have all the pieces of the puzzle, and if you change one piece of the puzzle you may have a completely different puzzle. A situation may appear to be entirely new, and any previous learning, even if retained, does not seem to be relevant. Everything that happens is unprecedented; past experiences and social rules are not linked to situations. All too often in FAS, the first choice is seen as the only choice, even when the solution clearly does not work. When someone with FAS appears to show no remorse for an action, it may simply be because the "possibilities" piece of the equation is not there.

Problems with Motivation

Reflection, something most people do in a split second, is a very complicated function. It comprises many inter-related thought processes, any one of which, if faulty, will radically alter the way in which one perceives relationships between people, things, or events. Reflection is control. Motivation is a problem when this function is missing, especially when there are no immediate or concrete outcomes for a behavior. Without the ability to reflect, to consider possibilities, to imagine outcomes, there is no reason for effort. Would you be motivated to make changes to things if you were unable to understand and keep the connections between the potential changes and your actions?

Problems with Time

Time is an anchor which places humans in relationship to others and their environment: We know where we are and who we are. Our anchor does not move. It allows us to swing in a circle - a cycle - and when one cycle is completed, we start over again, or incorporate the first cycle into a bigger one. Always, the anchor holds us in place, giving us crucial stability. With FAS, this anchor finds no secure hold, and the line of time simply unravels endlessly with no clear beginning and no clear end. People with FAS are frequently oblivious to our form of time. They do not show up for work on time, come back late from coffee, miss appointments, forget to eat, do not know what day of the week it is, and seem unable to complete a task even when they know the steps. Nothing gets done the way it is supposed to get done. Time does not pass, it simply is. Combine a poorly secured anchor with difficulty sequencing and with difficulty grasping the floating concept of "one" as it relates to time, (whether one hour, one class, one coffee break or one rinse cycle) and you may have great difficulty functioning. "Telling time" on a clock becomes a major frustration. It demands the generalization of concepts from math, the use of "before and after" concepts, approximation, an understanding of similarities and differences, knowing up from down and right from left, and the ability to hold *all* of this in your head at the same time, and not get distracted in the process. You must remember what you did not understand to start with and recognize the need to do the same thing all over again at some future point which remains unrecognized. Then, of course, you need to connect the numbers on the clock to the task at hand which is a different process altogether!

Most people possess an internal time clock that allows them to "sense" time, which is compatible with the natural order of things and into which concepts can be incorporated. People with FAS do not possess this clock

Missing Connections - the Spider Web Theory

The concurrent use of memory, cause and effect, generalization and time skills allows us to make logical, rational and sensible decisions about what should be done, when it should be done, and who should do it. FAS critically impacts one's ability to make sense of the environment, to communicate effectively, and to problem solve. Once the fall-out from problems requiring abstract thinking and memory are understood, it becomes very clear that people with FAS will have great difficulty in making sense of the world, even in the absence of problems with attention and activity. In fact, those children with FAS with good memory, higher IQ and without obvious attention problems seem to have even more problems, probably because our expectations are affected by what we see as fewer disabilities related to prenatal alcohol exposure. It has been my experience, however, that losing the edge on abstract thinking is all it takes to produce very significant functional deficits. Connectors are missing, and connections are what are crucial.

Consider how physical connectors work. A kitchen tap with a defective washer will spray water in all directions instead of in a steady stream; an electric kettle with an unseen break in the cord will boil water some of the time and not others; if the cord linking the VCR to the TV is not screwed in tightly, the picture will be fuzzy -three different connection problems, each of which causes the job to be incompletely or inconsistently done. How difficult would it be to wash your hands if the water was spraying all over? You have the soap, the scrub brush and the towel, but still your hands are not clean. The connector to bring the water in touch with your hands and the soap at the same time is not working. Transfer this idea to a mental process and you begin to have a sense of what is actually going on with people with FAS. You know the "what" and the "how" but you do not know the "when" and the "why." The "spider web" has broken, or perhaps the strand was never there.

Our job is twofold: Strengthen the "spider web" if we can, and catch the falling spider when we cannot.

Re-Weaving a Stronger Spider Web

What are the properties of a spider web? It is a resistant, flexible but fragile structure, firmly anchored on at least four points. A spider always builds a web the same way, using a series of connecting strands. The structure serves the spider well. If something breaks the connecting strands, the spider falls on a silken parachute which protects it from harm

The FAS spider web has an oversized weave so that information falls through. Sometimes the strands are weak and break easily. Other times the web is too sticky and information cannot pass along it. Frequently, the web does not connect where it is supposed to connect; it lacks order.

Like a spider web, our thought processes are intricately connected. If the strands randomly break, could we not, like the spider, reconnect them? We need some sort of support mechanism that can strengthen the strand sufficiently for a connection to occur. Could we build new strands across some of the holes in the web to spread the spider's weight over a bigger area? Could we loosen the perseverant glue when we need to? In fact, successful "accidental strategies" work precisely because they strengthen the spider web!

Understanding the spider web gives us the most crucial piece of this puzzle. We must realize that at *the heart of all compliance issues is a competency issue*. We have to move from seeing behavior as *noncompliance* to seeing it as *non-competence*. This critical perceptual shift allows one to stop "doing to" and start "doing with." It permits the art of spider web walking.

I experienced the most enormous relief when this change took place. Suddenly, I knew I was okay and so were my children. I began to hear them differently, to experience them differently, and finally, to understand them differently. I recognized if they could not adapt to the complex, complicated and constantly changing world, then I would have to be the one to adapt, because I am the one who is able to do so. Now I envision the environment as the spider web, our attitudes, advocacy, home and school as the anchor points, and supervision as the parachute.

Being part of a spider web is a difficult task. There are so many places where the web can break. I have learned to take responsibility for only those things over which I have control. The choice of reaction or response to a situation is mine. If I simply react, neither the child nor I learn very much; we simply experience another frustration. If I take the time to respond, which requires viewing a behavior or a problem in light of what I know about abstraction, I may be able to repair or strengthen the spider web. Responses take more time than reactions. Responding requires that I become a student of behavior, always asking what the underlying concept involved might be, and how I could potentially take what is abstract and make it concrete. It is a constant challenge, and there are as many setbacks as successes. How I view these setbacks makes the difference. Reweaving a spider web is a work in progress. One must not lose sight of the fact that the spider must continue to operate while the work goes on. If, in our desire to reweave, we fail to secure the anchor points or pack the parachute, we risk harming the web walker.

Reweaving the web itself can be done in as many different ways as there are ideas. *The key is to work smarter, not harder*. Reduce the need to generalize and comprehension is significantly improved. Use every sense to teach and connections are improved. Conceive of

time as a straight line instead of a circle and its passage can be taught. Use symbol language, color and music to fill in the holes and memory can be triggered. Develop routines which allow a child to "know" where he or she is. Fill in the blanks and relationships between things may become easier to grasp.

Although we cannot repair the spider web once and for all, we can strengthen it sufficiently to allow at least some improved functioning. Improved functioning leads to improved self-esteem, an important protective factor. Good self-esteem leads to a willingness to try.

Children and young adults with FAS are remarkable resilient people. If we can make the shift to incorporate the way they learn into the way we teach , we open up new possibilities for success.

A few years ago, a national "think tank" conference on FAS was held in Canada. My oldest daughter with FAS, who was 17 at the time, was asked to speak to the assembled delegates at the luncheon. She had attended the morning session and listened to a Federal Government Minister talking about the "victims" of prenatal alcohol exposure, and commenting repeatedly on all the things they could not do. Although she had not comprehended much of the speech, what she had understood bothered her. She fumed through the rest of the morning and I was a little concerned about a "rescue plan." However, I need not have worried. In fact, I have never been as proud of her as I was during her presentation. What she told the delegates at the end of her talk is the essence of the paradigm shift that all of us who live and work with FAS know to be true, "there are two things I want you to know: Do not call me a victim, and do not tell me what I can not do. Help me to find a way to do it."

If we can keep these two things in the forefront of our thoughts we will have moved from doing "to" to doing "with" for people with FAS.

We will have joined them on the spider web.

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